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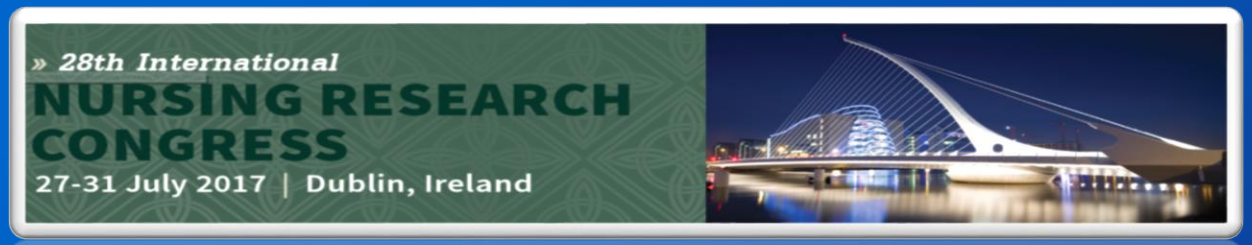

Saturday, July 29, Concurrent Session J
1:30-2:45 p.m. (1330-1445)

Symptom Burden of Critically Ill Patients at High-Risk of Dying: Reliability of Proxy Reports

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- Speaker has No Disclosures or Conflict of Interest related to this educational topic.

About MemorialCare……

Long Beach Memorial, Miller Children's and Women's Hospital, Long Beach MemorialCare Health System
569-bed, Academic, Level III Trauma Center, Level I, NICU
(100-bed) Long Beach, California, USA

Community Hospital Long Beach MemorialCare Health System
100-bed, Acute Care; 30-bed in-patient Behavioral Health; and Outpatient Services, Long Beach, CA, USA

Saddleback Memorial Medical Center
MemorialCare Health System
Laguna Hills, CA 92653, USA

Orange Coast Memorial
120-bed, Acute Care Hospital; and Heart Institute
Fountain Valley, CA, USA

Learning Objectives

1. Discuss the congruence of perceived symptom burden of (prevalence, intensity, frequency) and overall distress, as reported by critically ill patients at high-risk for dying, when compared to proxy assessment?
2. Discuss the challenge of assessing symptom prevalence and distress among high-risk ICU patients, whose physical and cognitive status waxes and wanes.
3. Describe symptom assessment instruments that have been tested supporting the use of proxies in providing valid assessment of critically ill family members.
4. Describe how proxy family members can serve as sources of information about patient symptom distress and care management among ICU patients' at high-risk for dying.

Background / Significance

- Good symptom control is an essential factor of care at end-of-life (EOL).[1] Patients with life-limiting illness or those actively dying, often experience substantial pain and/or discomfort, whether from their admitting diagnosis, procedures done in the intensive care unit (ICU), or related with a multiplicity of medical conditions.[1-2]

- For patient's who cannot communicate, ICU care givers use a variety of other means to assess patient discomfort, pain,[4] dyspnea, and other symptoms,[5-6] including assessment of psychological signs. Yet, no consistent method has been used to assess these symptoms and appropriately treat them. In fact, in many cases the provider or family member may recommend treatment based on the presumed discomfort or anticipated pain associated with a procedure, without having the ability to confirm the findings with the patient.

- Patient self-report is *gold standard*, however, ICU patients over time, may be unable to self-report, due to declining physical or cognitive function.[3] Thus, validating the congruence of 'Proxy' perceived assessments r/t to patient symptom burden is important, as often treatment decisions may be made by family/other proxy decision makers.[3-4]

- Assessment of patients' symptoms by proxies is available from studies performed outside the ICU, particularly among palliative care and other settings, yet, little research is available comparing proxy assessment with ICU patients.[4]

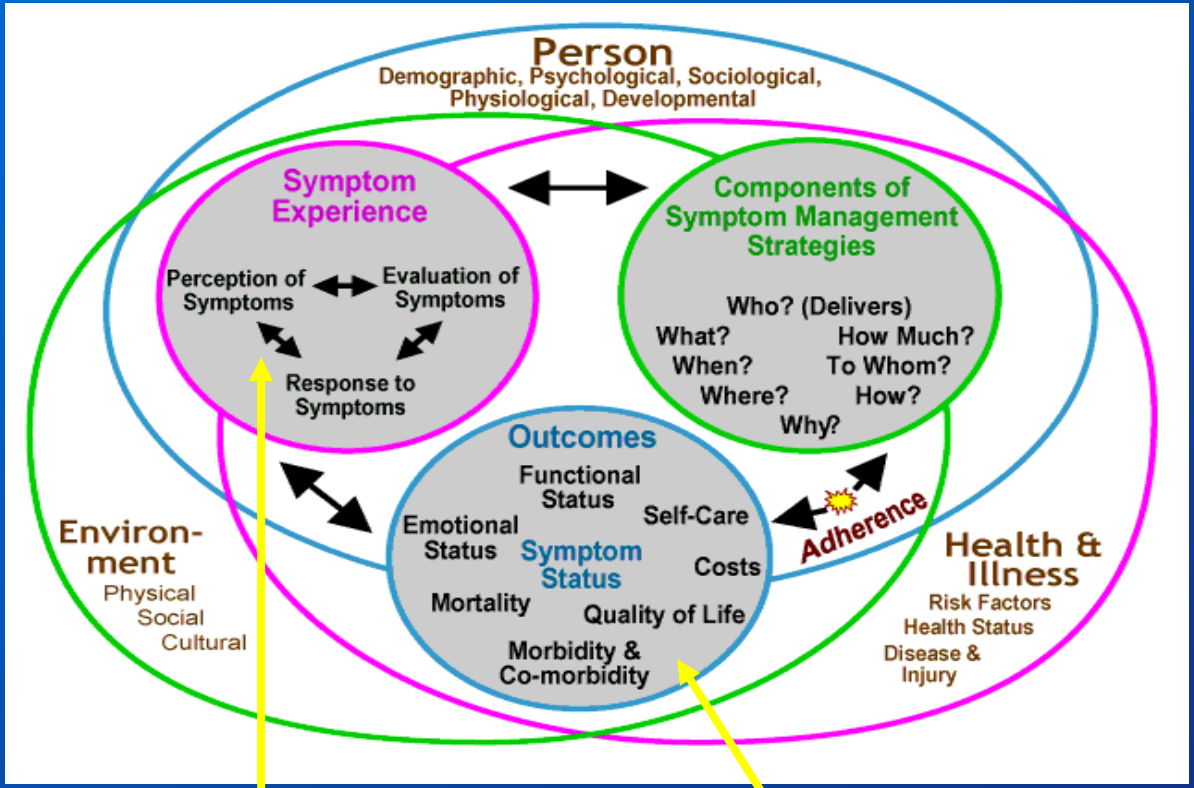
PURPOSE / AIM OF STUDY

- Purpose of this prospective, descriptive study was to examine the perceived symptom burden (prevalence, intensity, distress) of intensive care unit (ICU) patients at high-risk of dying; and to evaluate relationships among variables r/t the patient (age, gender, physiologic acuity, previous health status), and overall mortality.

- A secondary aim was to compare the ICU patient-rated symptoms (prevalence, intensity, frequency) and distress scores for concordance, with those rated by designated proxy-responders using the 'Condensed Memorial Symptom Assessment Survey (CMSAS), a14-Item, patient-rated survey to assess symptom burden'. [5]

Theoretical Framework

Symptom Management Conceptual Model



Patients' Perception of Symptoms
Patients' Evaluation of Symptoms
Patients' Responses to Symptoms

Symptom Status (Survival/death)

Figure 1: UCSF Symptom Management Conceptual Model and study variables. [6]

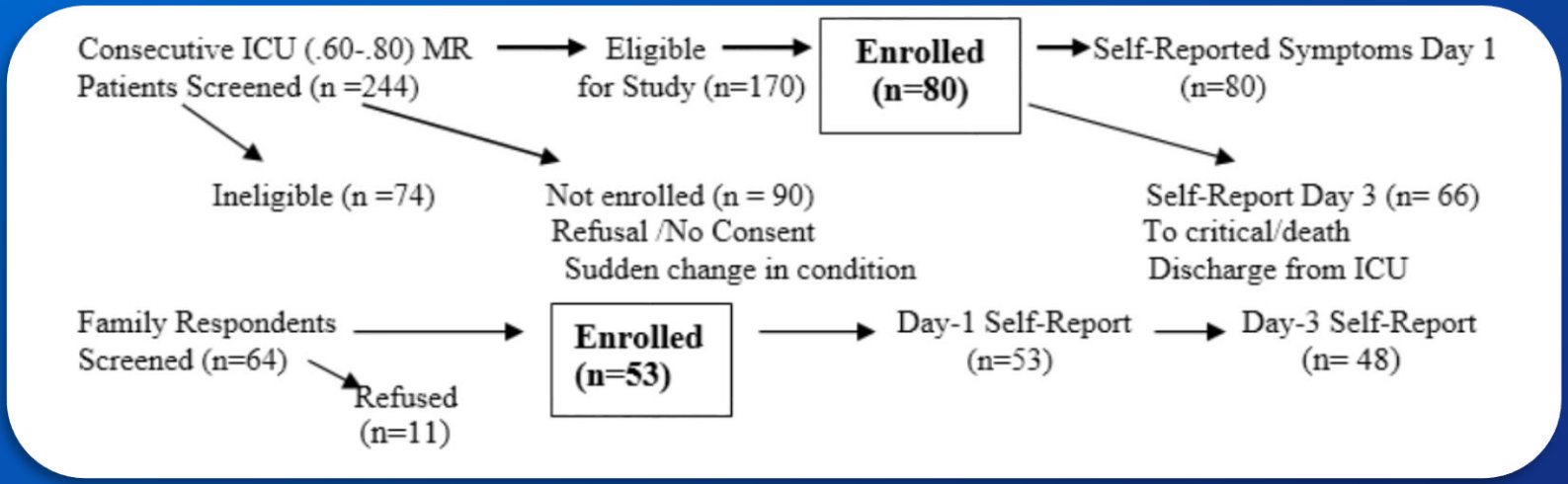
Methods

Design

- A descriptive, non-experimental, correlational design, with 2-data points, was used to measure study variables.
- Eligible patients were interviewed within 24 hours of admission and on day-three of care, to examine for any differences in patient ratings of symptom prevalence, frequency, and distress.

Setting/Sample

- Prospective study was carried out in a 53-bed ICU, at a 569-bed, tertiary care, Level I Trauma center. Convenience sample of **(*n*=80)** English/Spanish speaking adults, with variable diagnoses, along with 53 proxy respondents were enrolled.



Ethical Review

- This study was approved by the MemorialCare Health System (MHS) Institutional Review Board (IRB) Approval

Inclusion / Exclusion Criteria

PATIENTS

- Inclusion: 1) >18 years older; 2) speak, read/understand English/Spanish; 3) able to complete self-report instrument written or alternative method; 4) normal mental status, assessed by Richmond Agitation-Sedation Scale (RASS)[7] and the Confusion Assessment Method for the ICU (CAMU-ICU)[8] and; 5) probability factor of *60-80%* risk for hospital death.
- Exclusion: 1) diagnosis of cancer and receiving treatments; 2) principal diagnosis of dementia with altered cognitive status; or 3) altered LOC.

PROXIES: Defined as individuals who provided majority of emotional, financial, and physical support to patient prior to ICU admission. No legal relation or cohabitation with the patient was required.

- Eligibility: 1) non-professional, non-paid caregiver; 2) age ≥ 18 years; 3) telephone access; and 4) able to read and speak English /Spanish.
-

Study Instruments

- Richmond Agitation-Sedation Scale (RASS) [7]
- Memorial Symptom Assessment Scale (CMSAS) available in English/Spanish[5]
- Confusion Assessment Method for the ICU (CAM-ICU)[8]
- Demographic Information / Acute Physiology and Chronic Health Evaluation Prognostic Model (APACHE III) Score [9]

Study Instruments

PATIENTS

Day -1 - Demographic data retrieved from EMR; Condensed Memorial Symptom Assessment Scale (CMSAS) 14-Item, patient-rated survey to assess the symptom burden, **Days 1 / 3**

CMSAS was developed from Memorial Symptom Assessment Scale-Short Form (MSAS-SF), a 32-item multi-dimensional scale, developed initially for cancer patients [5]

CMSAS Multi-Dimensional Instrument- Three subscales

1. **Physical symptom distress (CMSAS-PHYS),**
   * Rates nine physical symptoms in terms of distress form 0 (none) to 4 (very much),
2. **Psychological distress subscale (CMSAS PSYCH)**
   * 3 Emotional symptoms (Worry, Sad, Nervous) frequency for 0 (not present) to 4 (almost constant)
3. **Total symptom distress score (CMSAS SUM).**

FAMILY

1. **Day -1 - Demographic questionnaire about themselves & their care-giving role for their loved one.**
2. **CMSAS symptom survey on Day 1 / Day 3, to measure their perception of the patients symptoms of previous week & in ICU.**

Patient CMSAS

Condensed Memorial Symptom Assessment Scale (CMSAS) Patient Version (English/Spanish)

Interviewer ID:_____ **Subject Code:**_____

How much did this symptom bother or distress you during the past 7 days?

Symptom	Present	Not at all	A little Bit	Somewhat	Quite a bit	Very much
Lack of energy	Y N	0	1	2	3	4
Lack of appetite	Y N	0	1	2	3	4
Pain	Y N	0	1	2	3	4
Dry mouth	Y N	0	1	2	3	4
Weight Loss	Y N	0	1	2	3	4
Feeling drowsy	Y N	0	1	2	3	4
Shortness of breath	Y N	0	1	2	3	4
Constipation	Y N	0	1	2	3	4
Difficulty sleeping	Y N	0	1	2	3	4
Difficulty concentrating	Y N	0	1	2	3	4
Nausea	Y N	0	1	2	3	4

How frequently did you experience these symptoms during the last week?

Symptom	Present	Rarely	Occasionally	Frequently	Almost constantly
Worrying	Y N	1	2	3	4
Feeling sad	Y N	1	2	3	4
Feeling nervous	Y N	1	2	3	4

OTHER SYMPTOMS

Identify any other symptoms that you believe bothered you during the past week. List them below & identify how distressful they were.	Not at all	A little Bit	Some what	Quite a bit	Very much
	0	1	2	3	4
	0	1	2	3	4
	0	1	2	3	4
	0	1	2	3	4

Family CMSAS

Condensed Memorial Symptom Assessment Scale (CMSAS) - Family Respondent (English)

How much did this symptom bother or distress your loved one in the past 7 days?

Symptom	Present	Not at all	A little Bit	Some what	Quite a bit	Very much	Not Aplicable (N/A)	Don't Know (D/K)
Lack of energy	Y N	0	1	2	3	4		
Lack of appetite	Y N	0	1	2	3	4		
Pain	Y N	0	1	2	3	4		
Dry mouth	Y N	0	1	2	3	4		
Weight Loss	Y N	0	1	2	3	4		
Feeling drowsy	Y N	0	1	2	3	4		
Shortness of breath	Y N	0	1	2	3	4		
Constipation	Y N	0	1	2	3	4		
Difficulty sleeping	Y N	0	1	2	3	4		
Difficulty concentrating	Y N	0	1	2	3	4		
Nausea	Y N	0	1	2	3	4		

How frequently did your loved one experience these symptoms during the last week?

Symptom	Present	Rarely	Occasionally	Frequently	Almost constantly	Not Aplicable (N/A)	Don't Know (D/K)
Worrying	Y N	1	2	3	4		
Feeling sad	Y N	1	2	3	4		
Feeling nervous	Y N	1	2	3	4		

OTHER SYMPTOMS

Identify any other symptoms that you believe bothered your loved one in the last week. .List them below & identify how distressful they were.	Not at all	A little Bit	Some What	Quite a bit	Very much
	0	1	2	3	4
	0	1	2	3	4
	0	1	2	3	4
	0	1	2	3	4
	0	1	2	3	4

Characteristics of the Sample

- Sample included 244 patients admitted to two ICU units of a large teaching hospital, with an APACHE III mortality risk ≥ 60%-100%, of those 170 were eligible.
- **N=80 patients were enrolled and able to self-report symptoms**
- Patient subjects ranged in age from 35-97 years, mean age 70 yrs., 50 patients (62.5%) were male and 30 female (37.5%)
- Martial status was mixed 35% married, 30% single, 23.8% widowed and 11.3% divorced
- Racial / ethnic composition was diverse 48.8% White, 22.5% Black, 15% Hispanic, 11.3% Asian and other 2.5%.
- Subjects were predominantly English speaking 81.3%, and 12.5% completed the survey in Spanish

Table 1. Patient Profile and Study Characteristics

Characteristic	M (sd)	N (%)
Primary ICU Admitting Diagnosis		
Respiratory	28	35
Gastrointestinal	11	13.8
Sepsis/Other	10	12.5
Cardiovascular	8	10
Renal	5	6.3
Neurological	5	6.3
Trauma	4	5.0
UTI Sepsis	4	5.0
Re-Admission to ICU from Discharge Units	13	16.3
APACHE III Chronic Health – Top Five		
Heart Problems	78	97.5
Respiratory Disease	59	73.8
Gastrointestinal Disease	58	72.5
Sepsis/Other	47	58.8
Renal Disease	45	56
Co-morbid Conditions		
1	30	37.5
2	29	36.3
3	13	16.3
4	5	6.3
5	1	1.3
APACHE III Predicted Mortality	Mean	± SD
First Day Hospital	69	± .09
Third Day Hospital	66	± .18
First ICU Day	49	± .14
Third ICU Day	45	± .21
APACHE III Score		
First ICU Day	97	± 23
Third ICU Day	81.9	± 33
Outcomes Mean ± SD		
ICU LOS	10	± 8.83
Hospital LOS	15.85	± 11.97
ICU Mortality	15	19%
Hospital mortality	2	3%
3-Month Follow-Up	16	25%

*Data are presented as mean ± SD or No. (%).
APACHE III = Acute Physiology and Chronic Health Evaluation III - Prognostic System
ICU = Intensive Care Unit; LOS = Length of Stay

Symptom Prevalence

- **98% of patients responding to symptom assessment were symptomatic!!!**

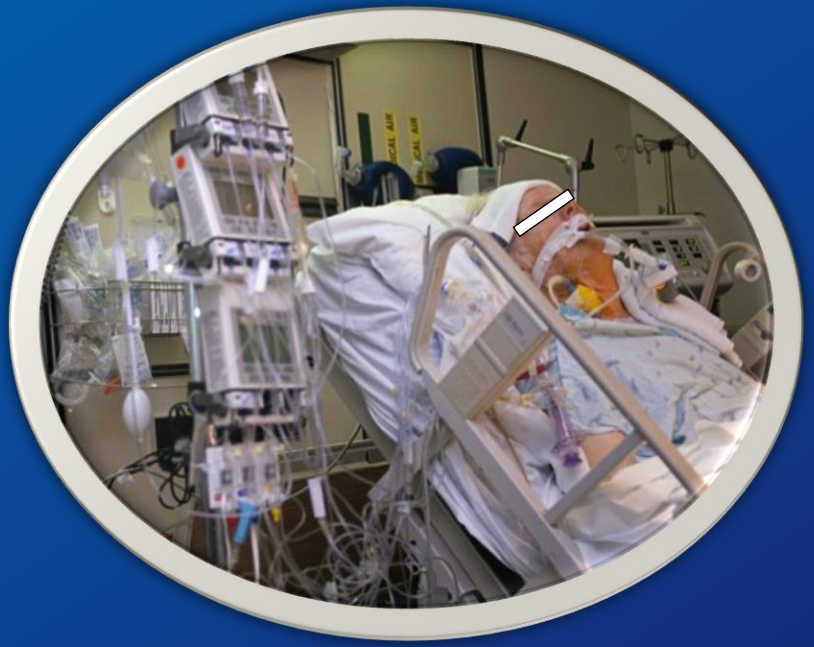


Table 2. Patient Symptom Distress Day 1 and Day 3

Means and Standard Deviations for Patient Reported Mean Symptom Distress Day 1 and Day 3

	Day 1 Bother or Distress in Past 7 days		Day 3 Bother or Distress since 2 Days Ago	
Physical Symptoms	n (%)	Mean Sx Distress Score (Std Dev)	n (%)	Mean Sx Distress Score (Std Dev)
Lack of energy (fatigue)*	79 (98.8)	2.96 (0.70)	65 (81.3)	3.80(0.44)
Lack of appetite*	76 (95.0)	2.30 (1.14)	64 (80.0)	3.18 (0.81)
Pain*	76 (95.0)	2.52 (1.21)	66 (82.5)	3.62 (0.66)
Dry mouth*	76 (95.0)	1.18 (1.22)	64 (80.0)	2.58 (0.88)
Weight Loss*	74 (92.5)	1.18 (1.31)	64 (67.5)	1.21(1.38)
Feeling drowsy*	78 (97.5)	2.66 (0.84)	64 (80.0)	3.60 (0.45)
Shortness of breath*	76 (95.0)	3.05 (0.88)	65 (81.3)	3.75 (0.66)
Constipation	70 (87.5)	1.07 (1.10)	58 (72.5)	0.99 (1.25)
Difficulty sleeping*	75 (93.8)	1.84 (1.42)	59 (90.8)	2.79 (1.06)
Difficulty concentrating*	79 (98.8)	2.79 (0.80)	64 (80.0)	3.40 (0.69)
Nausea	70 (87.5)	1.62 (1.28)	57 (71.3)	2.10 (1.26)
CMSAS-PHYS Subscale		2.19 (0.71)		3.07 (0.46)

CMSAS-PHYS Subscale is the average of the nine (*) Items

	Frequency of Symptom Occurrence in Past 7 days		Frequency of Occurrence Since 2 Days Ago	
Psychological Symptoms	n (%)	Mean Sx Distress Std Dev	n(%)	Mean Sx Distress Score (Std. Dev.)
Worrying	79(98.8)	2.58(0.70)	66(82.5)	3.50 (0.58)
Feeling sad	77(96.3)	2.20(1.02)	66(82.5)	3.48 (.68)
Feeling nervous	80(98.7)	2.33(0.88)	66(82.5)	3.42 (.72)
CMSAS-PSYCH Subscale		2.45(0.67)		3.46 (0.52)
CMSAS Total Distress Score		2.24(0.66)		3.17 (0.44)

CMSAS-PSYCH Subscale is the average of the 3 Psychological Symptoms; CMSAS Total Distress Score is average of all symptoms.

Table 3. Patient Symptom Distress Physiological vs Psychological Subscales

Mean Comparison of CMSAS Scales – Day 1 and Day 3

Scale	Day 1 (N = 80) Mean Sx Distress Score (Std Dev)	Day 1 (N = 80) Range	Day 3 (N = 66) Mean Sx Distress Score (Std Dev)	Day 3 (N = 66) Range
CMSAS-PHYS Subscale	2.19 (0.71)	0.20 – 3.56	3.07 (0.46)	1.16 – 3.91
CMSAS-PSYCH Subscale	2.45 (0.67)	1 – 4	3.46 (0.52)	1.67 – 4.0
CMSAS TOTAL SCORE	2.24 (0.66)	0.44 – 0.51	3.17 (0.44)	1.28 – 3.93

Note: CMSAS= Condensed Memorial Symptom Assessment Scale; PHYS=Physical; PSYCH=Psychological; Std. Dev = Standard deviation

CMSAS-PSYCH Subscale findings, are strong correlates to quality of life (QOL), (Chang et al., 2004). Scores >1 moderate to severe distress, and poor QOL.

Correlations of Chronic Health Conditions (comorbidities) and Symptom Distress

- Analysis revealed a number of chronic health conditions contributed significantly to the symptom burden among the study cohort, with eight of fifteen comorbidities correlating to significant symptom distress ($p<.05$) on Day 1 and Day 3, respectively.
- Symptom distress was significantly correlated with several of the top five admitting diagnoses to the ICU.
- **Respiratory disease was the #2 top admitting diagnosis to the ICU**. Patients with respiratory failure had multiple distressing symptoms on Day 1– lack of energy ($r=0.24$ $p= .03$); feeling drowsy ($r=.30$ $p= .01$); shortness of breath ($r=.30$ $p=.01$); difficulty concentrating ($r=.38$ $p=.05$) and a CMSAS PHYS distress score of ($r=.25$ $p=.03$).
- Trauma had a significant negative correlation with lack of energy ($r= -0.68$, $p = 0.05$, feeling drowsy ($r=-0.36$, $p = <.05$) and CMSAS-PHSY subscale ($r = -0.39$, $p = <.05$).

Correlations of Chronic Health Conditions (comorbidities) and Symptom Distress

- Hematological disease is significantly positively correlated with feeling drowsy ($r = 0.26$, $p = 0.03$) and nausea ($r = 0.37$, $p = <.05$);
- Muscular skeletal disease has a significant negative correlation with SOB ($r = -0.24$, $p = .05$) and difficulty concentrating ($r = 0.24$, $p = .05$).
- GI disease is significantly positively correlated with dry mouth ($r = 0.23$, $p = .04$), weight loss ($r=.30$ $p =.01$) and CMSAS-PHYS Subscale ($r=0.24$ $p= .03$).
- Cerebral vascular accident has a significant negative correlation with difficulty sleeping ($r= 0.28$, $p = .01$) and is significantly positively correlated with difficulty concentrating ($r= 0.22$, $p = .05$).

Conclusion: Disease severity, mortality risk and a patients chronic health status, appear to be an independent factor associated with higher symptom burden and decreased quality of life. Age was not an independent factor by itself.

Patient Self-Report vs Proxy Report

- A secondary aim was to compare the critically-ill patient-rated symptoms (prevalence, intensity, frequency) and distress scores for concordance, with those rated by designated proxy-responders.

- This provides a more comprehensive approach to understanding the differences in various raters, regarding the multidimensional nature of symptoms at EOL and their impact on different aspects of quality of life.

RESULTS

Proxy Respondent Characteristics

- Proxy respondents (PR) -any close family member or significant other, designated by the patient. There was no attempt to create a matching dyad of patient with a specific proxy respondent.

- Of the 80 patients who agreed to participate in the study, 16 did not have family or a designated proxy respondent (PR). Sixty-four PRs were identified, although 11 were unavailable/or declined to participate. A total of 53 PRs agreed to participate.
- Mean age of PRs was 59 yrs., range, 25-92, 30.2% were male and 69.8% female. Racial/ethnic composition was diverse, 43.4% White, others were Black (17%), Hispanic (20.8%), Asian (15.1%) and other (3.8%).

Table 4. Proxy Relationship to Patient

Relationship to Patient		
Spouse	23	43.4
Patient's Child	22	41.5
Patient's Sibling	3	5.7
Patient's Parent	2	3.8
Partner	3	5.7
Legal Surrogate for Patient		
Yes	46	86.8
No	7	13.2
Primary Care Giver for Patient		
Yes	37	69.8
No	16	30.2
Patient's Residence		
Home	34	64.2
Long Term Care	13	16

STUDY RESULTS

Proxy Respondents-Symptom Assessment

- Overall proxy raters reported an average of 9.75 out of 11 physical symptoms assessed.
- Most common and distressful symptom reported by proxy raters on day-1 was pain (98.1%), with a symptom distress score mean of 2.73 (SD=1.10).
- Three other physiologic symptoms rated at (96.2%) were lack of energy (fatigue) M = 3.32 (SD=.539); (lack of appetite) M = 2.44 (SD=1.30) and (feeling drowsy) M = 2.85 (SD=.835), respectively on a scale of 1 to 4.

Table 5. Means and Standard Deviations for Mean Symptom Distress Day 1 and Day 3-Proxy Raters

	Day 1		Day 3	
	Bother or Distress in Past 7 days		Bother or Distress since 2 Days Ago	
Physical Symptoms	n (%)	Mean Sx Distress Score (Std Dev)	n (%)	Mean Sx Distress Score (Std Dev)
Lack of energy (fatigue)*	51(96.2)	3.32(.539)	46(86.8)	3.94(.199)
Lack of appetite*	51(96.2)	2.44(1.30)	45(84.9)	3.30(.629)
Pain*	52(98.1)	2.73(1.10)	46(86.8)	3.72(.420)
Dry mouth*	30(56.6)	1.36(1.31)	45(84.9)	2.72(.807)
Weight Loss*	44(83)	1.70(1.53)	26(49.1)	1.93(1.57)
Feeling drowsy*	51(96.2)	2.85(.835)	45(84.9)	3.59(.500)
Shortness of breath*	52(98.1)	3.03(.900)	45(84.9)	3.80(.423)
Constipation	37(69.8)	.864(1.05)	37(69.8)	1.05(1.22)
Difficulty sleeping*	47(88.7)	1.83(1.36)	42(79.2)	2.59(1.15)
Difficulty concentrating*	49(92.5)	3.05(.705)	46(86.8)	3.65(.400)
Nausea	45(84.9)	1.67(1.42)	45(84.9)	2.38(1.21)
CMSAS-PHYS Subscale Day-1 (mean/Std. Dev.)		2.54(.540)		3.33(.321)

CMSAS-PHYS Subscale is the average of the nine (*) Items

	Frequency of Symptom Occurrence in Past 7 days		Frequency of Occurrence Since 2 Days Ago	
Psychological Symptoms	n (%)	Mean Sx Distress (Std Dev)	n (%)	Mean Sx Distress Score (Std. Dev.)
Worrying	52(98.1)	2.65(.814)	48(90.6)	3.58(.498)
Feeling sad	50(94.3)	2.54(.838)	48(90.6)	3.71(.504)
Feeling nervous	50(94.3)	2.66(.772)	48(90.6)	3.54(.582)
CMSAS-PSYCH Subscale		2.58(.706)		3.61(.431)
CMSAS Total Distress Score		2.56(.502)		3.40(.298)

CMSAS-PSYCH Subscale is the average of the 3 Psychological Symptoms; CMSAS Total Distress Score is average of all symptoms.

Patient and Proxy Respondent Concordance

- Cohen's Kappa statistic was included to measure the agreement between the patient and family member ratings of symptom presence. A general rule of thumb for significance for the Kappa statistic is any value that is greater than .6 indicates significant agreement between the two groups.

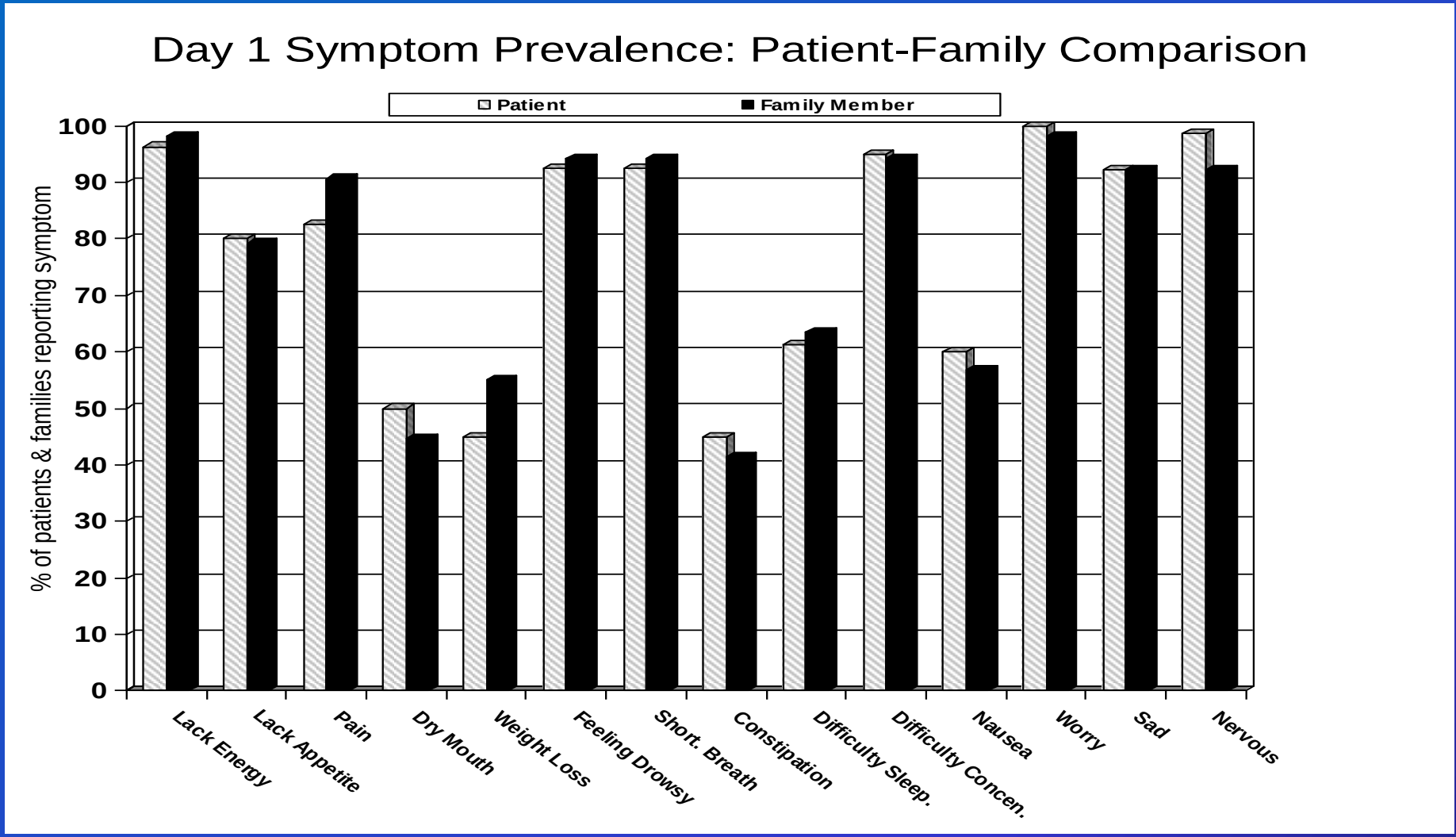
- The Chi-Square results indicated that on Day 1 there was significant relatedness between the patients and family members for the physiological symptoms, but not for the psychological symptoms.

- Kappa statistic for Day 1 symptoms was not as clear in which there was significant agreement between patients and family members for Lack of Energy, Lack of Appetite, Weight Loss, Drowsy, Difficulty Sleeping, Difficulty Concentrating, and Nausea, while there was no significant agreement between Pain, Dry Mouth, Shortness of Breath, and Constipation.

Table 6. Concordance between Patient and Proxy Raters on Day 1 and Day 3 CMSAS Symptom Prevalence

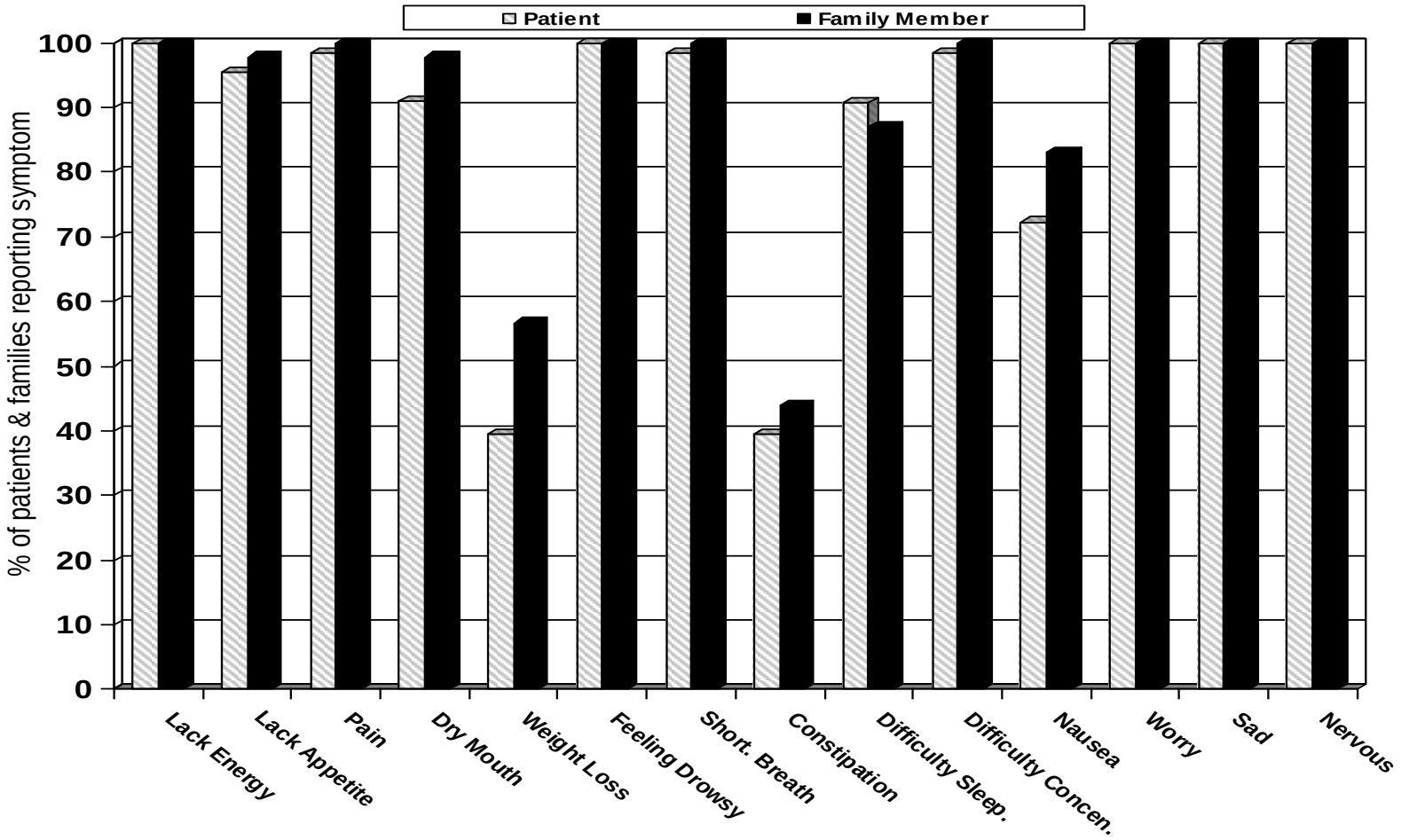
	df	*n*	X^2 (p-value)	*Kappa*
CMSAS Symptom Day 1				
Lack of Energy	1	53	25.99 (p<.05)	.66
Lack of Appetite	1	53	22.80 (p<.05)	.66
Pain	1	53	18.15 (p<.05)	.57
Dry Mouth	1	38	9.89 (p<.05)	.49
Weight Loss	1	49	25.42 (p<.05)	.72
Drowsy	1	52	21.72 (p<.05)	.65
Shortness of Breath	1	52	5.24 (p=.02)	.30
Constipation	1	41	9.90 (p<.05)	.49
Difficulty Sleeping	1	52	23.22 (p<.05)	.67
Difficulty Concentrating	1	53	22.16 (p<.05)	.65
Nausea	1	51	26.51 (p<.05)	.72
Sad	1	51	0.37 (p=.54)	-.09
Nervous	1	52	0.09 (p=.77)	-.03
CMSAS Symptom Day 3				
Lack of Appetite	1	44	0.50 (p=.83)	-.03
Dry Mouth	1	43	0.14 (p=.71)	-.04
Weight Loss	1	27	12.71 (p<.05)	.64
Constipation	1	39	14.45 (p<.05)	.58
Difficulty Sleeping	1	42	0.72 (p=.40)	.13
Nausea	1	45	29.01 (p<.05)	.78

Table 7. Concordance of Symptom Prevalence: Patient/Proxy Comparisons (Day-1)



Prevalence of physical and psychological symptom prevalence reported by patients and proxies. The figure shows the percentage of patients (n=80) and proxy respondents (n=53) providing self-reports, who responded that the symptom was present.

Table 8. Concordance of Symptom Prevalence: : Patient/Proxy Comparisons (Day-3)



Prevalence of physical and psychological symptom prevalence reported by patients and proxies on day-3 of ICU Care. The figure shows the percentage of patients (n=66) and family respondents (n=48) providing self-reports, who responded that the symptom was present.

Patient and Proxy Respondent Concordance

- The Chi-Square results indicated that on Day 3 there was significant relatedness between the patients and family members for some of the physiological symptoms Weight Loss (k=.72), Constipation (k=.49), Nausea (k=.72), while none of the psychological symptoms were evaluated due to constant values.
- The Kappa statistic for Day 3 symptoms indicated that there was significant agreement between patients and family members for Weight Loss and Nausea, but not for Constipation.
- Overall, these results point to some agreement between patients and family members regarding the presence of CMSAS physiological symptoms, with higher agreement on Day 1 than 1 than Day 3.
- There was no significant agreement found between patients and family members regarding the presence of CMSAS psychological symptoms.

Conclusions

- The use of an integrated symptom assessment approach, involving patient and proxy ratings is of great value across the spectrum of critically ill patients. For cognitively intact patients, a consensus of patient and proxy assessments would be an ideal outcome. Even with discordant assessments, the use of such an integrated approach could help address apparent differences in symptom assessment among patients, and various raters.

- For cognitively impaired patients, the selection of individuals who may best understand and represent the patient's symptom experience would also be an ideal outcome. The current study is the first attempt, to examine the reliability of patient and proxy symptom ratings concurrently among critically ill patients and families, using the Condensed Memorial Symptom Assessment Survey (CMSAS).

- Every effort was made to include family/proxy respondents, in order to determine the utility and accuracy of proxy ratings of patient symptoms, and different explanatory factors for patterns of disagreement between the two groups. Findings are similar to more research work examining proxy and patient assessment among terminally ill patients. [10-16]

Conclusions

- This study identified ICU patients *near death* experience a significant burden of multiple symptoms, yet receive limited treatment for significant symptom distress. A need for widespread symptom management strategies with proven effectiveness is indicated.

- Data also confirmed that proxy reporter's perception of patient symptom burden can a reliable alternative, and should be used when patients can no longer self-report.

- This study examined multiple symptoms and a factor analysis of multi-factorial risk factors that correlate significantly with high symptom burden.

- Further research is needed to test new evidence-based interventions to serve as a practice standards in the delivery of consistent, high quality care for all dying patients to minimize unnecessary suffering.

Thanks

Questions?

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